**One Family’s Experiences**

*Bruce and Kelly Stahlman did not expect their twins to be born 3 months early at 28 weeks gestation.*

BRUCE'S LETTER

*Relativity.*

*Whenever we discuss speed or velocity (an object's speed and its direction of motion), we must specify precisely who or what is doing the measuring . . . each observer feels stationary and perceives the other as moving. Each perspective is understandable and justifiable. As there is symmetry between the two space-dwellers, there is, on quite fundamental grounds, no way of saying one perspective is "right" and the other "wrong." Each perspective has an equal claim on truth. (Greene, 2000, p. 28)*

Special needs kids weren't visible during the 60s and 70's when I progressed through public school. Once in a while, you'd see bus No. 16 making an afternoon run, shorter than all the other buses and rumored to be carrying retards. We didn't really understand what that meant, of course, any more than we understood what it meant to be Negro or Jewish or Communist. We gave no thought, shallow or otherwise, to what having a disabled sibling or child might imply.

They'd always been out there, unseen, hidden away by parents and convention, probably ashamed or afraid. More likely out of exhaustion and confusion from having nowhere to turn, no one to help and no one to empathize out of personal experience.

Mike's brother, Tom, had Down's Syndrome. Strong as an ox, he was never without his beloved tinker toy wheel on the end of a coat hanger. We'd always see him while playing cards in Mike's basement. There was a sense of loss, years later, when I heard Tom had passed away. I wish I'd known him better.

Rob was transformed from a cocky high school student to a drooling semi-vegetable as a result of a boating accident. He'd play cards, too, but he was unintelligible most of the time and he moved so slowly. His parents got divorced. I lost track of Rob in short order.

That pretty much covers my formative experience with disabilities. So it's fair to say I wasn't overly prepared for the arrival of our second and third sons, Mark and Eric, 28-week preemies. One alone would have been a shock, two crossed the line into farce. It started with an extended stay in the Intensive Care Nursery. When Eric, the younger twin, finally arrived home he sported a newly repaired heart , apnea monitors, oxygen tanks, and joined his brother in fussing most every night due to their inability to consume enough calories. Sleep deprivation was the worst because it precipitated a cascade of dysfunctionality throughout the house.

I could go on and on. Cerebral palsy is a complicated disorder. Both boys have gastrointestinal tubes for feedings, a regimen of medications and supplements to help with everything from muscle spasm to bowel movement, and a fleet of assistive devices. "Hospital trips for specialist review, surgeries, botox injections, and an endless stream of therapist and nursing assistants invading our privacy have become something of a routine that's emotionally draining yet monotonous. A sales professional by training, my wife has become an expert at navigating the private and public health care systems out of necessity, an educational consultant out of conviction and an advocate out of desire.

It would have flatly been impossible to survive this institutionalized anarchy any other way than by simply growing into it, over the years, one day at a time. In the process, the twins have gone from pre-med thesis material to become our sons with rich, individual personalities, idiosyncrasies and foibles just like "normal" kids. While we wish for them more than is presently possible, we take great pride in their many and significant accomplishments: Eric babbling away at dinner and sitting by himself in his red rocker; Mark learning to use his talker; Eric driving his power chair and endlessly playing and rewinding the Lion King with a remote controller all by himself, and Mark laughing hysterically whenever his older brother gets in trouble. We love them as any parent loves his children. We love reading at bedtime, tickling and teasing, going to a baseball game and swimming. And Eric's Make-A-Wish trip to Give Kids the World Village and Disney World in Florida to meet his favorite Radio Disney DJ was one of the most inspirational events of my life.

People in the disability community threw us a life- line early on by acting as guides through the maze of public services access. It's beyond astonishing that the richest society on earth makes people traverse a gauntlet to receive even the most basic services. It's worse when you realize how many more get no help or respect from agencies purportedly designed for that purpose. In the process, my politics have changed from conservative to liberal. Both my wife and I have served in various charitable capacities to give something back to the community because it's important to remember you're in a lifeboat with others.

Our oldest son, Jay, gets a lot of credit. I assume he's been impacted in ways I can't comprehend, but mainly for the good. He produced a video of his brothers and spent a day in a wheelchair for a school project last year, something that would never have occurred to me when I was his age.

Our marriage has become stronger over the years as we've grown with the family. My wife is fond of saying life is what you do every day. That's true, but I could certainly live without changing my ten-year- olds' diapers, administering tube feeds, doing the "clean and jerk" whenever they need to be moved and watching Barney tapes for the umpteenth million time and counting. This last point is particularly heinous-no parent should be made to endure Barney for ten years without receiving a Congressional medal.

The emotions, surgeries, finances, the life over- all certainly isn't what I'd expected or planned. Does God work in mysterious ways? Probably. Do I put more stock in theology versus philosophy? Depends on the day. Are Mark and Eric better off than Chinese, Bosnian, or Rwandan kids with CP? Unquestionably. Do other people see it that way? I guess it's relative.

Bruce R. Stahlman

Littleton, Colorado

September 26, 2002

*Kelly follows with a letter that she hopes will clarify the relationship between parent and teacher and help teachers understand parents better.*

A letter to teachers, current and future:

As a mother of twins with cerebral palsy, I want to thank you for taking the time and making great efforts to care for my children. Without you I would be lost.

Next, I would like to explain, one by one, some of my actions and reactions. Please be patient.

First. After reading the vignette "Story" in the book, Changed by a Child, I finally understood why I keep telling you the same story over and over and over. The vignette talks about the excruciating details that I need to convey, because it is all still so real and so raw to me. That, like a spider spinning its web, retelling my story allows me to connect my old life to this new, overwhelming reality.

My story is the vehicle that makes the trip of survival and allows me to cope with the present.

Second. In caring for children with disabilities, a large part of the care is emotional, so the teacher/parent relationship is, by definition, also emotional. We are both investing all that we can into my children, yet we frequently seem to be at odds. Please work WITH me. Give careful consideration to the information that I bring to the table, because it comes as the result of sweat and tears. It is also my role in your system, as a parent, to push the envelope, to be looking ahead, and to be asking for everything that I can to support my child. I will still be here when I am 80 and they are 50, and we shall still be "doing the best we can."

Third. Asking "how are things going" at the start of our meetings gives necessary information. My sleep, the children's health, and life overall will be things that affect our conversation and how effectively I am able to communicate.

Last. Never forget that I am grateful for all that you do. It becomes tiring to always say thank you, because that is the nature of our life. In fact, one of the blessings of a disability is that it frequently brings out the best in others. I never forget a kindness, even years later, but it still gets old saying "thank you" as a way of life. Nevertheless, THANK YOU.

Kelly of Stahlman

Mother of 3 sons, Jay, 13,

Mark and Eric, 10-year-old twins

with cerebral palsy due to prematurity

**Addendum to Bruce Stahlman's letter:**

**August 16,2006**

Mark and Eric turned 14 this past weekend and their first day of high school is tomorrow. No doubt all parents think time passes quickly, but I still have vivid memories of their stay in the ICCN. They remain great kids with some unique challenges for our family as they inexorably become young adults. These fall into three general categories:

1. Logistic- The physical exertion to move them through space has increased dramatically over time. Simply, they continue to grow and gain weight while my wife and I and the attending CNAs age, so lifting them for wheel chair positioning, hygiene, sleep, etc. while avoiding injury to them and us has become more difficult. We are presently in the final stages of home modification project that involves combining bedrooms; enlarging the bathroom and installing a ceiling lift system to address these concerns. Finally, we continue to explore evolving technology for communication purposes for both boys including Dynavox upgrades for Mark, who is non-verbal, to PC applications for Eric to afford him greater access to the Internet.

2. Behavior- Coupled with the normal hormone changes of adolescence are overlay symptoms of ADD particularly in Eric, the more mobile twin. We suspect there's also a growing psychological awareness of their general situation vis-a-vis other kids, for example, as their older brother enters his junior year of high school. We're seeing a lower tolerance of schedule changes, higher demand for activity repetition, and increased incidence of temper tantrums accompanied by hitting, both outward and self-directed. Behavior modification techniques have been at the forefront of ongoing discussions with school personnel and the CAN, but results have been mixed. This is a challenging problem given the paradox of life skill training to set appropriate boundaries vs. the need to actively parent through these important years.

3. Medical- My wife estimates each boy has had nine or ten surgeries over the course of their lives and more are on the horizon. Recently some disturbing changes in Eric's spine have been observed and he'll likely require an involved stabilization procedure. Mark will likely have non-weight bearing ankle bones fused to counteract the effects of overpronation. Thankfully, the logistics changes noted about should be a big help here for recuperation and ongoing care.

Of course this type of clinical situation analysis doesn't capture the daily joy of parenting kids with special needs. They are exceptional, funny, loving, and interactive in their own ways, and I can't imagine the family without them.

**A FEW JEWELS FROM THE STAHLMAN**

**FAMILY SURVIVAL SKILLS**

Why me?

Why not me?

Ignorance is bliss; knowledge is power.

Kids with disabilities take much longer to go to the next stage. They wear you out. Patience and endurance are required, with lots of support!

In some ways it gets easier; in some ways it gets harder, and in some ways it just gets different as you go through stages and ages.

God never gives you more than you can handle. He did at our house! The miracle is to watch God's grace at work in the midst of all the chaos.

My kids teach the art of being with the gift of presence, the miracle of doing, and the priority of having.

No matter where you are, someone is better off and someone is worse off.

Equipment is the quintessential mixed blessing:

It can be social barrier which prevents the community from seeing the child/person, a management nightmare and just plain awkward while being vital to the child's participation in life. My greatest nightmare is that Eric and Mark will learn the low expectation of observing life instead of participating in it.